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Background studies on day care
(See pg 81)

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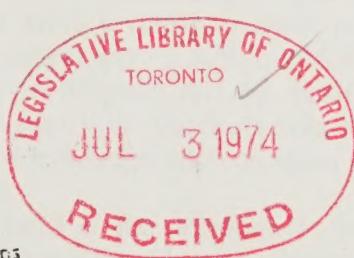
September 1971

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Photograph on the cover:

A playgroup for 20 children with cerebral palsy, spina bifida, autism and other handicaps which opened at Walsall Wood, Staffordshire, last year is one of the increasing number being formed for handicapped children (see p.19)

By courtesy of Walsall Observer



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Handicapped and Under Five

Pre-school provision for the majority of handicapped children remains 'a pipe dream'—but not for a group in the Yeovil area where local initiative has established a playgroup three mornings weekly. Sheila Fox, social worker for The Spastics Society's west region, describes the efforts to launch it and its subsequent progress

Living with Handicap (1970) highlights the diversity of pre-school facilities made available by the various local authorities for handicapped children. Some authorities are excellent, forward-looking and imaginative. One fairly small county borough, for instance, provides a special playgroup for mentally handicapped, emotionally disturbed and socially deprived children; the day school for severely subnormal children accepts them from the age of three; a playgroup for maladjusted children operates at the local hospital's psychiatric unit; the hospital and L.E.A. jointly run a children's cerebral palsy unit, while there is a nursery class for the deaf and partially hearing and additional domiciliary auditory training by specially trained health visitors. Moreover, day nurseries admit a small number of physically or mentally handicapped children and a small purpose-built unit for handicapped children has just been added to an existing day nursery.

Unhappily, excellent provision such as this is rare. As long as local authorities have permissive, not statutory, powers for the under-fives, and relevant services for handicapped children remain so uncoordinated, pre-school provision for the majority will remain a pipe dream.

Pre-school experience for the handicapped child appears to operate on an inverse ratio—the greater the handicap the less the provision. For the severely subnormal child it is minimal. If local authorities had to contribute to the upkeep of their children who go into subnormality hospitals, more might be done to prevent the children from being admitted initially or to allocate increased budgets to the hospitals to improve their conditions.

Decision to take the Initiative

When local authorities are unable or refuse to make provision themselves, they sometimes put untold obstacles in the way of voluntary organisations prepared to raise money to do so. Although unfortunate incidents may have occurred in the past, coordination on all levels, both statutory and voluntary, should be the present aim. This would happen more frequently were the purpose of the exercise—the handicapped child and his family—kept consistently in the forefront of everybody's mind when discussions take place.

Aware of the social needs of some severely handicapped children in Devon and Somerset—and their

parents' need for relief—I decided four years ago to take the initiative in trying to provide them with some pre-school experience.

Two Outlets Found

After a long and tortuous search to find a playgroup willing to experiment, eventually two young leaders admitting limited experience with handicapped children offered to help three mornings a week. With rather lukewarm blessing from the local health departments involved, I placed two spastics, first a five year old boy, then a severely subnormal girl of 11 no bigger than a child aged four, in these two playgroups for normal children. Although both children eventually died, in the 18 months they attended the playgroups the change in them was remarkable. Their handicaps were too great for intellectual improvement but their delight and response at being with their peers was obvious to everyone. The other children became aware of their differences but were kind and helpful, with the exception of a disturbed boy who resented the extra attention given to the handicapped five year old and tended to be destructive and spiteful. The benefit to the mothers and to the other children in the group made me realise that pre-school experience for the handicapped child was as essential as for normal children.

Shortly afterwards, comparing notes with an experienced mental welfare officer, we found that between us we had no fewer than 12 children under seven years for whom no facilities whatsoever were available in the Yeovil area apart from occasional physiotherapy at the nearby hospital. Six were severely cerebral palsied and subnormal and the others were E.S.N. or S.S.N. Further enquiries from other colleagues, notably health visitors, quickly established that with the inclusion of children with mainly physical handicaps such as spina bifida, the list had grown to 18.

Establishing the need is the prerequisite for making provision, so together we thought and planned. Despite repeated requests to the health department, no regular help was forthcoming although they were willing to pay towards the cost for two weeks' holiday care for each child. As a means test was operated, the expense frequently prevented the parents from taking advantage of the offer and, in any case, this was not the true need.

The mental welfare officer went off on a course, leaving me to brood. During her absence, three of my



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mothers, in utter despair, asked for their children to be admitted to subnormality hospitals—they could manage no longer. A year later, when my colleague returned, we decided something must be done in the interests of the families as a whole. If the local authority was unwilling or unable to provide support, voluntary help must be enlisted.

As we saw it, these children would benefit from playgroup experience comparable, if modified, with that of other groups. Accommodation was to hand in Yeovil: a newly decorated, large and centrally heated church hall with a well equipped kitchen, good storage space and adequate toilet facilities which the governing board offered at reasonable letting terms.

Formation of a Steering Committee

The first step was to form a steering committee of interested knowledgeable people aware of the size of the problem and willing to go to any lengths to resolve it. My colleague, who knew the area well, suggested six members, who were magnificent from the start. The chairman, a retired company director, maintained order discreetly when our enthusiasm ran away with us and our bank manager treasurer never at any time let us overspend—important in small ventures such as this. Our secretary, a retired headteacher of the junior training centre, brought years of experience to bear on our plans while a doctor's wife, as a committee member of various other organisations, knew what avenues should be explored when raising money. The fourth lay member, with a mentally handicapped child of her own, was in a unique position to guide our thoughts and plans.

An analysis of running costs indicated, that with the necessary staff: children in the ratio of 1:2 the playgroup would cost £1,200 a year, excluding transport, running for three mornings per week. This figure may appear high but staff salaries and their travelling expenses were a large item. We had quickly to accept, therefore, that unless we could persuade the local authority to provide or at least help with the children's transport costs, the playgroup could not materialise. Our catchment area was wide and attempting to bring the children in by volunteers and return them to outlying country areas was simply not practicable.

A Spate of Donations and Volunteers

The medical officer of health agreed there was a need—but was uncertain at first about meeting it in this way and sceptical about the health committee's attitude. Would they, with their limited budget, feel this to be a legitimate need, remembering that they had only permissive powers and not statutory obligations towards these young children?

To the small committee straining at the leash to put their plan into effect the delay seemed intolerable. Meeting for the first time in December 1969, their New Year appeal to a variety of interested bodies had received

an immediate response. Money had poured in—large donations from different groups—cheques from individuals—special efforts here—sponsored walks there. Young married women, with a variety of trainings, had offered to work at a lower rate than their professional qualifications demanded. This was a pioneer effort in which they wanted to be involved from the beginning. They were anxious to experiment while their own small children benefited from, as well as being an asset to, the playgroup. The people of Yeovil had taken the plight of the children to their hearts; no effort was too great. With such kindness and goodwill it seemed right that such a playgroup should be opened.

It was hard being patient when so much time already had been spent on planning and thinking and when the response from parents had been overwhelming. 'This is something—something we need for our children. Let it be started as quickly as possible,' they had said.

Perhaps the balance was finally tipped by the outstanding generosity of the regional hospital board. Acknowledging that several of the children would have to be admitted to subnormality hospitals if the playgroup were not started, they donated the magnificent sum of £500. The health committee gave a further £200 towards staff salaries and agreed that existing transport could be used.

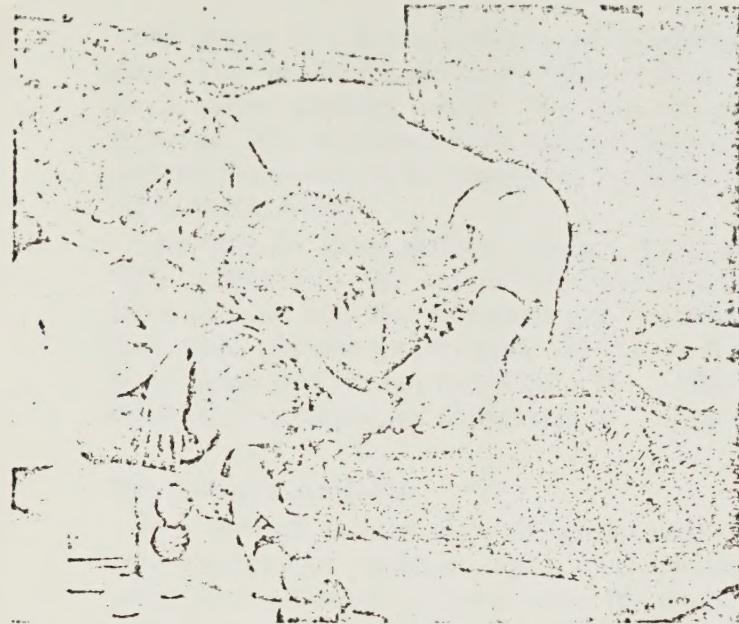
Final Preparations for the Opening

In the weeks before the playgroup finally opened, in April 1970, the committee and staff sought advice and help from every quarter. It was important that the right equipment and methods should be used. Observation visits were paid to another similar group in the next county and correspondence passed back and forth with Dr. Faulkner of the Stevenage Opportunity Group, a nursery group for handicapped children under seven whose mothers meet at the same time to discuss their problems and receive advice from professional workers.

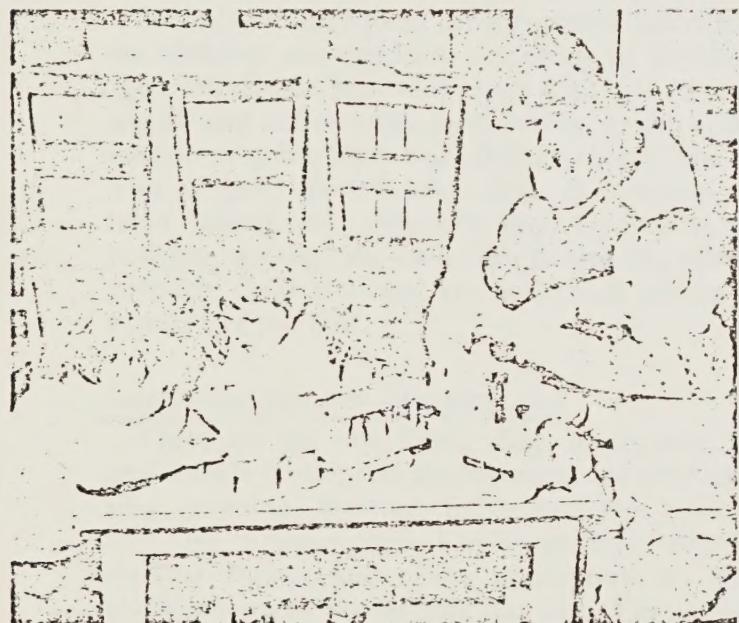
A worth while afternoon was also spent at a busy nursery unit for cerebral palsied children where the experienced senior physiotherapist gave invaluable help over equipment. A Fleet Air Arm contingent nearby volunteered to make toys and equipment while the staff rubbed down and painted small chairs, bought for 12½p apiece from the I.e.a.

Throughout, my mental welfare colleague was the brains and the brawn of the whole plan. She coordinated, wrote appeal letters, helped to buy apparatus, painted toys, consoled anxious parents, encouraged apprehensive staff, brought her expertise to every committee meeting, pressurised groups of people into making special fund-raising efforts, and in every way possible worked to make the playgroup a viable concern.

Late in May, the occupational therapist and equipment clerk from The Spastics Society's London headquarters exhibited a wide variety of aids and equipment to parents and professional workers. This was particularly valuable for the parents who were able to discuss their



A cerebral palsied boy, unable to sit, plays on the floor with the help of a wedge, encouraged by a staff member

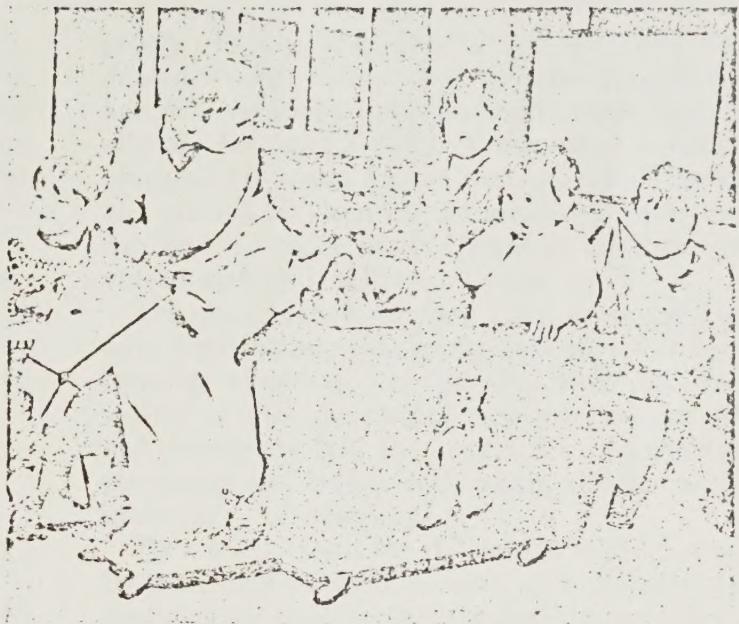


One of the playgroup staff guides children in play activity designed to aid sensory development

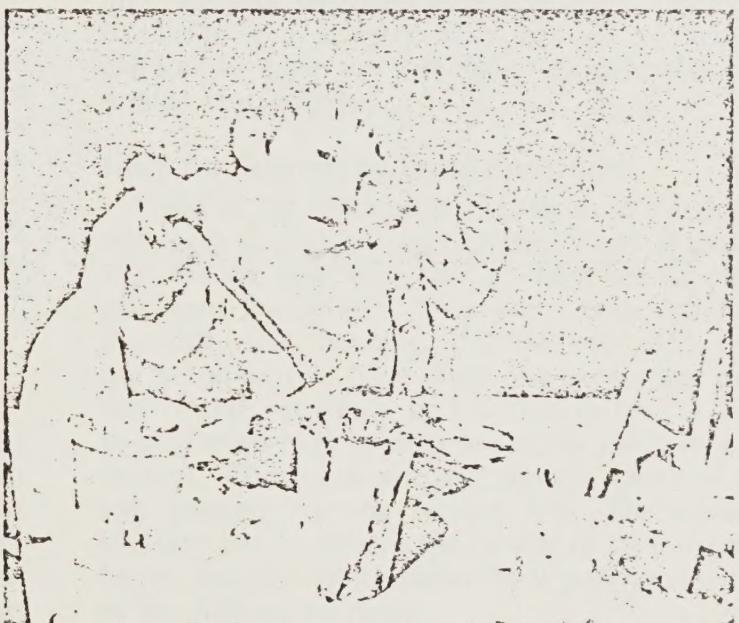
Photographs by courtesy of W. H. Rendell, Esq.

own children's needs with staff experienced in the problems of cerebral palsied children. Literature was freely available including an up-to-date brochure of items provided free under the national health service and the procedure for obtaining them.

As transport was run in conjunction with the local junior training centre, it was at first reluctantly decided to close the opportunity group during the schools' summer holidays. On reflection, and in response to fervent appeals from parents facing long summer days without any break from their handicapped children, the committee decided to keep the playgroup open but move into the junior training centre so that some of the



A group of children join in unstructured play with large wooden toys



A severely multiply handicapped child builds up his former skills after a brain operation

younger children from the centre could also attend. This project was costly. The committee had to pay for transport, but £100, they felt, was not too high a price to pay for the relief it gave to the families and evident stimulus and contentment to the children themselves. This venture was only made possible, however, by the generosity of willing volunteers, including able and enthusiastic senior school girls, and by the fact that parents continued to pay 17½p per session.

Late in 1970 my colleague, the physiotherapist who attended nearly every session, and I met with the mothers to discuss the playgroup's effect not only on their children but on themselves and the rest of the family.

We found it a heartwarming and humbling experience. Our primary concern throughout had been for those young children whom fate had so grievously damaged. We were only too aware of the deficiencies and the drawbacks of the group but we had felt all the effort worth while.

Listening to these mothers, though, gave us just a little insight into the unremitting burden carried by these families and the difference just this small relief had made. As one mother said, 'At least we feel somebody cares--we are not forgotten'. This is the crux of the matter—we must not allow them to be forgotten.

The Group's Activities

It is now 18 months since the group began. Thirty-two handicapped children, aged nine months to 6½ years, have attended, six more come for physiotherapy and eight are on a waiting list. The total includes 10 with cerebral palsy, six with spina bifida, four with multiple handicaps, two mongols and one maladjusted child.

In the mornings there are structured activities (when the children are grouped according to developmental age), self-chosen play and group activities to encourage speech and action—like story-telling, action songs, percussion or going for a walk in the garden. The children have a quiet period after their mid-morning drinks, toilet training and—extremely important—physiotherapy in a play setting. At some time during the morning the younger children have an individual period with a member of the staff.

Integrating the Non-Handicapped

There are big toys like a slide, trampoline, tricycles and Wendy house, and opportunities for sand and water play, painting, drawing, finger painting, table puzzles and toys. Foam wedges, Cnailey trolleys, baby buggies, walking frames and chairs appropriate to individual children's needs are in constant use. The introduction of a tortoise, rabbit and dog has been particularly welcomed by a small severely physically handicapped girl.

To integrate the ordinary children successfully and to prevent them from being bored, their own interests have had to be sustained. They face the problem of watching their own mothers devoting much of their time to other children but can be helped if the mother turns it into a partnership: 'We will do this together.' The staff are encouraged to look after their own children first—this helps to allay their own feelings of guilt and anxiety.

The non-handicapped children have matured considerably since joining the group. They may, admittedly, satisfy their own needs first but they then proceed to satisfy the needs of their handicapped companions. It is, however, noticeable that they feel more at ease with the younger children, not willingly admitting the handicapped child of their age into their own

group. This is partly because they cannot accept the demands made on them by children whose chronological age may be theirs but who intellectually and emotionally are far behind them. From our experience at the playgroup it would appear that pre-school handicapped and normal children can be integrated up to about age five but the older normal child is reluctant to be involved with his handicapped peers.

The main problems that have arisen in the group have been mainly due to the fact that this has been a learning situation for everyone involved. Despite a variety of individual training no one, paid or otherwise, had previously had the experience of running such a playgroup and coping with young children with such a multiplicity of handicaps.

To a great extent the difficulties have been overcome by joint discussions, a pooling of knowledge, attending conferences, reading about others' experiences and inviting knowledgeable people to the group to comment and offer constructive criticism. We realise, however, that more is now required and we are currently looking into ways of widening our knowledge about specific handicaps and learning new methods of helping the children to move towards their own potential, however limited that may be.

Need for Support by Local Authorities

Three of the children have gone on to nursery school and seven to junior training school. Four of the original 18, who are now five years or older, are keeping their places in the group. They are grossly handicapped, physically and mentally, and the local authority does not yet appear to have made any permanent plans for their future. It would be heartless to turn them away, to send them back to their homes, to admit they are not wanted. There are already, though, children of two, and younger, on the waiting list. The earlier such children can be offered the benefit of such a group the better, but the health department permits a maximum of 20 children, no more.

Now that the education authorities have accepted responsibility for all children, normal and handicapped since April, it is to be hoped that they will appreciate the value of such playgroups as an interim measure until they are in a position to provide pre-school experience themselves.

It is also to be hoped that they will be quick to appreciate how inadequate to date have been the facilities for the more severely handicapped young child. This nettle must be grasped straightaway while overall future needs of handicapped children are being considered. It could be fatally easy, at this stage, to overlook children like the four left in the playgroup. It is the responsibility of all of us to see this does not happen.

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